

POSITION PAPER ON SUPPORT SYSTEMS
FOR FAMILIES OF MENTALLY RETARDED PERSONS

INTRODUCTION

For the purposes of the report, Family Support Services refer to those mental retardation services which are complimentary and/or supplementary to residential services and regular day programs such as Vocational programs, Adult Day Care Services, Child Day Care Services (e.g., Early Intervention and Infant Stimulation programs), and those programs and services which are the responsibility of the Pennsylvania Department of Education.

I. CURRENT STATUS

1. LEGAL BASE

The primary legal base for the establishment of support services for the families of mentally retarded persons is derived from Sections 201 and 301 of the Mental Health and Mental Retardation Act of 1966. Section 201 empowers the State to assure the availability and equitable provision of adequate mental health and mental retardation services for all persons who need them. Section 301 mandates that local authorities, in cooperation with the Department, must insure that the following mental health and mental retardation services are available:

Short term inpatient Services

Outpatient Services

Partial Hospitalization Services

Emergency Services

Consultation and Education Services

Aftercare Services

Specialized Rehabilitation and Training Services

Interim Care of Mentally Retarded Persons

Intake and Referral Services

Most of the services which are considered "Family Support Services" are within the realm of "Specialized Rehabilitative and Training."

In addition to those services which are mandated, Section 301(e)(3) also provides that local authorities also have the power to establish "any other service designed to prevent mental disability or the necessity of admitting or committing the mentally disabled to a facility." It is that section which provides the general authority for the establishment of family support services not specifically mandated by the Act. A primary example of a family support service program which was initiated under the authority provided by Section 301(e)(3) is the Mental Retardation Family Resource Services Program.

2. PRINCIPAL PROGRAMS THROUGH WHICH FAMILY SUPPORT SERVICES ARE CURRENTLY OFFERED

There are four basic programs (funding mechanisms) currently available to the County MH/MR Programs for the provision of Family Support Services. These include (1) The Base Program, (2) The Family Resource Services (FRS) Program, (3) The Community Living Arrangements (CLA) Program, and The Title XX Programs(4)

- A. BASE ALLOCATION - It is through the non-categorical base allocation that the nine services mandated by the Act of 1966 are provided.

Because "specialized rehabilitative and training services" are mandated, Family Support Services may be/are provided through the base allocation. The scope of Rehabilitative and Training services are loosely defined in Sections 5226.11 and 5226.12 of the DPW Title 5200 Regulations.

B. FAMILY RESOURCE SERVICES PROGRAM

Initiated late in Fiscal Year 1972-73, the FRS Program is the primary vehicle for the provision of community-based support services for families of mentally retarded persons. For the family, the FRS Program has as its purpose to provide adequate supportive resources within the community to enable the family with a retarded member to maintain that member at home with minimal stress or disruption of the family unit. For the individual, the purpose of the FRS Program is to provide adequate supportive resources within the community to enable the mentally retarded individual to remain in a family context in a community setting, thus leading as normative a life as possible. The principal services provided through the FRS Program include the following:

Respite Care

Family Aide Sitter/Companionship Services

Homemaker Services

Transportation

In-Home Therapys

Family Education/Training

Recreation/Socialization/Leisure Time Activities

The provision of FRS Services to mentally retarded persons/families is under the authority of the DPW Title 9058 Regulations.

C. COMMUNITY LIVING ARRANGEMENTS (CLA) PROGRAM

Although the CLA Program is a residential program for mentally retarded persons whose primary residence (home) is the CLA facility, there is one component of the CLA Program which provides a short-term residence for mentally retarded persons when their families need a period of relief. Originally termed "Crisis Assistance" in the Program & Budget Guidelines for Special Living Arrangements for Retarded, when the regulations were promulgated in February, 1973, this component of the CLA Program had been re-named "respite care" in the practical operation of the program. Thus, one specific family support service, i.e., respite care, is available through the CLA Program.

D. TITLE XX

For Fiscal Year 1980-81, four of the six MR Title XX-eligible services are considered within the scope of Family Support Services. These are Homemaker Services; Service Planning/Case Management; Socialization/Recreation; and Transportation.

3. SCOPE OF MR FAMILY SUPPORT SERVICES CURRENTLY OFFERED

There are two important points that must be made before any listing of currently available family support services is presented. First of all, the authority for currently offered support services and for establishing almost any kind of new support service already exists within the scope of the MH/MR Act of 1966. Secondly, mental health services of a support nature for mentally retarded persons and their families are or should be available through the mental health service system. These include services such as family and group therapy, clinical family counseling, etc.

Those Family Support Services currently available to mentally retarded persons and their families through the MH/MR system include at least the following:

- A. Respite Care (FRS,CLA.Base)
 - In-Home
 - Host Home
 - Group Homes
 - Medical Facilities
- B. Sitter Services - children (FRS,Base)
- C. Companionship Services - adults (FRS, Base)
- D. Homemaker Services (FRS, Base, Title XX)
 - Training in home management skills
 - Basic homemaker activities
- E. Transportation (FRS, Base, Title XX)
 - To Regular Day Programs
 - To Recreation/Socialization Programs
 - To Medical Services
 - To other appropriate activities

F. Recreation/Socialization (FRS, Base, Title XX)

- Summer Recreation
- Year-round Programs
- Special Events
- Residential Camping
- Day Camping

G. In-Home Therapies

- Visiting Nurses
- Physical Therapy
- Occupational Therapy
- Speech Therapy
- Audiologic Services
- Visual-Mobility Training
- Vocational Therapy
- Therapeutic Recreation
- Dental Hygienics
- Behavioral Programming

H. Family Education/Training (FRS, Base)

- Family Dynamics
- Parent Effectiveness Training
- Behavior Management
- Genetic Counseling
- Family Planning
- Other Topics Associated with Mental Retardation

I. Rehabilitative Therapies (Base, FRS)

- Speech Therapy
- Physical Therapy
- Audiologic Training
- Mobility Training
- Travel Training
- Dactylogic Therapy
- Related Paramedical Services

J. Case Management/Service Planning (Base, Title XX)

K. Public Education & Information (Base)

L. Other Special Innovative Support Services

4. STATISTICAL SUMMARIES OF SUPPORT SERVICE PROGRAMS

A. BASE PROGRAM -

The number of mentally retarded clients/families receiving family support services to this date through the base allocation cannot be retrieved because the County MH/MR Programs have not been required to report that type of information with any degree of reasonable specificity.

B. FRS PROGRAM -

(a) Attachment 1 gives a fiscal summary of the FRS Program from Fiscal Year 1972-73 through Fiscal Year 1979-80.

(b) Attachment 2 gives a breakout of the number of persons/families receiving FRS Services and of the state and local expenditures for those services by service category for Fiscal Year 1978-79. Data is available for the statewide FRS Program and on a Region by Region basis.

(c) Attachment 3 identifies the annual average (median) per person costs for FRS Services by Region for FY 1973-79-

(d) Attachment 4 identifies the annual average (median) per person FRS Service costs for the statewide FRS Program for Fiscal Year 1978-79.

(e) Attachment 5 gives a summary of the total expenditures and the unduplicated number of Persons/Families served by the FRS Program for FY 1977-78.

(f) Attachment 6 gives a breakout of the State and Local expenditures for FRS Services by service category on a County, Regional and Statewide basis for FY 1978-79.

(g) Attachment 7 gives a breakout of the number of persons receiving FRS Services by service category on a County, Regional and Statewide basis for Fiscal Year 1978-79.

C. CLA PROGRAM -

Data on the unduplicated number of clients receiving respite care through the CLA Program on an annual basis is not currently available. It is, however, reasonably estimated that as many as 1000 - 2000 different families have received respite care services through the CLA Program during the past two Fiscal Years.

D. TITLE XX PROGRAM -

Cumulative statistics on the number of mentally retarded persons/families who have been/are receiving support services through the Title XX program are not currently available within the Department.

E. NATURE OF CURRENTLY AVAILABLE DATA ON FAMILY SUPPORT SERVICES -

Currently available information on Family Support Services has primarily been collected by the personnel responsible for the management of the particular programs at the Central Office level, e.g., FRS, CLA, Title XX, etc. Until the recent introduction of the Consolidated Community Reporting System (CCRS), County Programs have not routinely been required to report data on clients systematically by age range, type and degree of specific handicapping condition. Currently available data has been reported by number of service recipients and by service category.

5. TRAINING FOR SUPPORT SERVICES - RESPONSIBILITY AND AVAILABILITY

Within the framework of the MH/MR Act of 1966, there is no specific mandate for the Commonwealth to provide training for providers of mental retardation services. However, Section 301 (e)(1) does provide that local authorities have the power to establish programs designed to train personnel (providing services for the mentally disabled). Furthermore, Section 305 (2) states that the County Mental Health & Mental Retardation Administrator shall have the power and his duty shall be to "insure that County Mental Health & Mental Retardation Services required by the Act are available."

Section 305 (10) then states that the Administrator has the responsibility to _____ take such steps and adopt such measures as are necessary for the proper discharge of his duties. It seems, therefore, to be relatively clear that the primary responsibility for the training of providers of family support and all other mental retardation services rests - at least by law - with each County Program, not with the Commonwealth.

The role of Central and Regional Office personnel in regard to training providers of Family Support Services has basically been within the realm of technical assistance on a "request" or "as needed" basis. There have been, however, a few instances when OHR staff have identified a specific need for training providers of support services and have developed training programs and packages to address those needs. One example of a current OMR-sponsored effort to train providers of a support service is the joint project with Penn State to train generic community recreation agency in how to develop and implement services for developmentally disabled persons. As a general rule, however, these types of efforts have been initiated by individual OMR staff with an interest in and responsibility for specific service areas. They have not resulted from a global OMR training plan.

With the establishment of the OMR Training Committee within the past year, the development and implementation of a coordinated OMR Training Plan appears to be in progress. Heretofore, OMR had not established a systematic process for planning and implementing programs to meet the needs of service providers for training.

The target date for the completion of the general component of the OMR Training Plan is July of 1980. The availability of training activities for specific service areas such as family support systems will not be dealt with until after the general mental retardation components have been developed.

6. SUMMARY OF OUTSTANDING PROBLEMS OF THE CURRENT FAMILY SUPPORT SERVICES SYSTEM

A. LACK OF ADEQUATE FUNDS FOR SUPPORT SERVICES -

Although the Department has consistently given strong verbal endorsement for the provision of support services to families of mentally retarded persons, funding for these services has never received an adequate level of support. Traditionally, OMR, DPW and the Governor's Budget Office have placed primary philosophical and financial emphasis on the continued growth of the Community Residential Service System while acknowledging the need for day programs and support services for community clients but not providing adequate funds for these programs and services. Consequently, we have created a system in which we have many places for deinstitutionalized persons to live, but inadequate day programs and support services for all community clients. By placing a disproportionate emphasis on Community Residential Services, we in fact have done little to encourage or help families of mentally retarded persons to maintain a retarded family member within the home situation.

The bottom line is that it is probably more economically feasible but less normalizing for a family to place a retarded member in a State/County subsidized residential program than it is for the same family to try to maintain the retarded member at home as an integral part of the family unit. We essentially appear to have capitalized on available monies without giving adequate consideration to helping families to keep their retarded children out of government-subsidized residential programs. Government-subsidized Community Residential Services are indeed important, but the family is still the basis of our society. It is not only sociologically sound, but also economically feasible that we intensify our efforts to help families to maintain a retarded member within the family unit where possible. To accomplish that goal, more adequate funding for support services programs such as FRS is absolutely crucial.

B. PROBLEMS ASSOCIATED WITH DISTRIBUTION OF SERVICES -

It is reasonably obvious that many County MH/MR Programs do not make a wide range of support services available to the families of mentally retarded persons. Certain County programs concentrate totally on very few services such as transportation and recreation, with little or no emphasis on other necessary support services. There are a number of possible reasons why County programs do not provide a wide array of support services to provide necessary relief for families of retarded persons.

These include, but may not be limited to the following:

- Lack of adequate funds for Support Services
- Lack of adequate MR Staff on the Staff of the Administrator or BSLJ
- Lack of initiative
- Lack of providers of Support Services
- Lack of awareness on the part of parents/families of Support Services potentially available.

C. TRANSPORTATION DEMANDS -

Beyond any doubt, the one support service which has placed the greatest and most intense demands upon the MR Support Services funding resources is Transportation. There appears to be three basic reasons for this trend. The first reason relates to the rapidly increasing costs of fuel. The second reason relates to the fact that people who formerly drove their family members to services are no longer willing or able to continue that practice because of the cost of fuel. Consequently, they are demanding subsidized transportation services from the County MR Program. The third reason is that there are simply more persons in the community MR system requiring transportation services because of deinstitutionalization efforts. Clearly, the MR system cannot control the rising costs of a gallon of gasoline. If we are to curb the amount of MR expenditures for transportation services, it will probably be necessary to develop policies which limit the types of services to which MR persons/families can receive transportation subsidized by the MR system.

D. PROBLEMS ASSOCIATED WITH THE ABILITY OF SOME COUNTY PROGRAMS TO MEET THE LOCAL MATCHING FUNDS REQUIREMENTS -

Within the past two years, a small number of County programs have indicated that the local authorities are becoming less and less willing to increase the local tax base to be able to meet the 10% matching requirements for 90/10 funded MH/MR Services. Although any effort to increase funding resources for family support services must take this potential problem into account, the problem itself is currently not considered to be of state-wide significance at this point in time.

II. STRATEGIES TO IMPROVE THE CURRENT SERVICE SYSTEM

1. EXPANSION OF THE FRS PROGRAM BUDGET -

There are at least 2,046 mentally retarded persons/families who required existing FRS-eligible services but who will not receive these support services because of inadequate funding. To make the existing FRS-eligible services available to these persons/families, the annual FRS budget must be increased by an additional \$2,526,810. That amount is based upon the annual average per person cost of \$1235 in state dollars for FRS services. Since the PRR mechanism appears to be the most appropriate vehicle for expanding the fiscal scope of a program, DPW/OMR must give highest priority to supporting a Family Resource Services PRR designed to expand the fiscal base for the program.

2. POSSIBLE EXPANSION OF THE CURRENT FRS SERVICE CONCEPT TO INCLUDE A MEDICAL COMPONENT -

Although the Innovative Services component of the current DPW 3058 Regulations for the FRS Program provides the basic authority for the provision of nearly any type of new support program service, one area which is not covered (but for which requests have been made) relates to the purchase of necessary medical equipment/supplies for client use. These include wheelchairs, medically prescribed lifts and related equipment. It may be possible to include these medically-related supports within the scope of the FRS Program, especially for those persons who cannot obtain such devices through other programs such as H.A.. It is estimated that the FRS Program budget would have to be increased by a minimum of \$50,000 to add this medically-related component to the scope of FRS-eligible services. That figure is based upon an allowance of \$500 per family to accommodate a total of 100 requests per year.

3. DEVELOPMENT OF PROVIDER TRAINING PACKAGES OF SPECIFIC FRS SERVICES-

In conjunction with the efforts of the OMR Training Committee, provider training packages for specific FRS services can be developed for use by County Programs for preparing agencies and individuals to deal more effectively with mentally retarded persons. These training models would have a two-fold purpose. First, they could be utilized by County programs to evaluate the extent to which potential providers meet the necessary requirements to provide specific support services. Second, they can be utilized as the course content for County-sponsored training programs for those provider agencies whose staff have not had the necessary orientation/training to provide specific services for mentally retarded persons and their families.

Although such packages may be developed for almost any support services area, there are currently identified needs for training models which deal with the following areas:

- Respite Care
- Sitter/Companionship Services
- Recreation (spinoff from the current recreation training project)
- Family Education/Training
 - Behavior Management
 - Self Help Skills
 - Parent-Child relationships
 - Understanding mental retardation
 - Other types of programs which assist parents and other family members to deal appropriately with a family member who is mentally retarded

4. DEVELOPMENT OF AN OMR POSITION STATEMENT ON CLIENT TRANSPORTATION SERVICES

Since the OMR/DPW cannot control the rising costs of fuel, it appears to be necessary to take one of two courses of action to deal with the negative impact that excessive expenditures for transportation are having on the provision of a broad range of support services to MR clients. The one course of action would be to request additional funds-perhaps even a separate appropriation - for client transportation. The second course of action would be to develop an Office/Departmental policy or position statement which would either limit the client transportation to certain types of programs or would limit the total amount of expenditures which County programs could encumber for transportation services.

Although both of these alternatives merit further consideration, the second one appears to be a more realistic approach to handling the current transportation problems with which State sponsored programs are confronted in these inflationary times. Restricting client transportation to the most necessary services and only for the most needy clients would be consistent with the approach that all families must take to combat the rising costs of all types of transportation services.

There is also another important issue that must be addressed when considering continued support for client transportation in the face of high inflation. It does not appear to be legitimate to require that families of non-handicapped persons continue to subsidize an unrestricted service (transportation) for families of handicapped persons when unrestricted transportation opportunities are no longer available to the former group because of the tremendous impact of inflation.

It therefore seems apparent that the Department develop and enforce

a policy regarding client transportation which would place restrictions on the quantity or types of services available.

III. POSSIBLE NEW MR INITIATIVES

There is much latitude within the authority of Section 301 (d)(7) of the Act of 1966 for the provision of support services for mentally retarded persons. There is also some latitude within the scope of the FRS Program (c.f. Section 9058. 12.8 of the Title 9058 Regulations) for the expansion of those efforts which can be determined to be support program services.

Furthermore, Section 301 (e)(3) already provides the authority for the establishment of any new initiative which would be determined to be a support program service.

It seems, therefore, that essential ingredients of Family Support Services are already in place within the Commonwealth. The basic problem pertaining to the lack of availability of such services is directly related to the lack of adequate funding to make those services available to as many families as possible who need them.

There are, however, three different initiatives which the Department/Commonwealth might undertake to provide additional incentives to encourage and assist families to maintain a retarded family member within the home. These initiatives may be considered financial incentives and merit DPW/OMR consideration.

1. CASH SUBSIDY PROGRAM FOR FAMILIES OF MENTALLY RETARDED PERSONS -

Under this type of program, parents of a mentally retarded person living at home whose family income falls below an established level would be eligible for a monthly cash subsidy from the State for extraordinary costs associated with caring for the handicapped individual. Such a program could appropriately be operated through Pennsylvania's County Board of Assistance Offices. The cost of the program to the State cannot immediately be determined; but the principle variables that would have to be considered in determining statewide costs would include the following:

- A pre-established eligible family income level.
- An established monthly subsidy rate
- A determination of the number of families eligible for the subsidy based upon income level.

Since such a cash subsidy program does not fall within the nature of MH/MR services, as provided by the Act of 1966, the creation of such a program probably would necessitate the enactment of new legislation (1) to establish the program and (2) to provide the funds to support the program.

2. CASH GRANT PROGRAM FOR NEEDY FAMILIES FOR SPECIAL PURCHASES NECESSARY FOR THE CARE AND MAINTENANCE OF A MENTALLY RETARDED PERSON -

Under this type of program, needy families could apply to the State for grants for special purchases which they need to enable them to continue to maintain their retarded family member within the home. Such items might include hydraulic lifts, stair glides, motorized wheelchairs, hospital beds, and even basic appliances such as washers and dryers.

Since this type of program would involve the provision of a financial supplement rather than a program service, it would not fall within the scope of the Act of 1966. Consequently, the creation of such a program would necessitate the enactment of new legislation to (1) establish the program and (2) to provide the funds to support the program.

Furthermore, such a program would involve grants to families for special purchases necessary for the care and maintenance of mentally retarded persons, it would seem appropriate that the Office of Mental Retardation would have the primary responsibility for developing the program, establishing criteria for grant eligibility for the program, and for the statewide operation of the program. There is no realistic way to determine the potential costs for initiating this type of new initiative. It would, however, seem appropriate to establish the program as a Pilot Project for up to three years with a maximum State allocation to be determined arbitrarily. .

3. TAX DEDUCTION PROGRAM FOR FAMILIES OF SEVERELY/PROFOUNDLY RETARDED AND/OR MULTIPLY HANDICAPPED PERSONS -

Under this type of program, parents of severely/profoundly retarded and/or multiply handicapped persons residing at home would be eligible for a tax credit to be applied against their annual responsibility for payment of State income taxes. This type of program exists in North Carolina where parents are required to submit a "proof of retardation" statement with their annual state income tax form to be eligible for the tax credit. The creation of such a program obviously would involve the exactment of a new tax law. The estimated impact on State revenue cannot immediately be determined.

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